

A GOAL FOR LIFE

For Friends and Supporters of the Ara Parseghian Medical Research Foundation



Dear Friends,

As spring takes hold, the Foundation is busy with grant reviews, preparations for the upcoming Niemann Pick Type C Scientific Conference and fundraising across the country. The upcoming events bring hope of advances in the development of treatments for NP-C, just as spring is a hopeful reminder of new life.

These events are only possible because of the army of volunteers who make them happen and the many who attend and support them. Today and every day, I pause to pay a grateful tribute to all of you who have made a difference in the fight against NP-C.

Thank you,

Cindy Parseghian

Students and Researchers Collaborate for NP-C

Through successive BIOS courses led by Professor Kasturi Haldar, the Center for Rare and Neglected Diseases at the University of Notre Dame collaborated with Dr. F.D. Porter and Nicole Yanjanin, M.S.N. of the NIH's NP-C Natural History Study, to show that pre-med college students can be trained to assist with developing natural history for NP-C. They are now also collaborating with the National Niemann Pick Disease Foundation (NNPDF) and helping families to directly submit their medical records and videos, from which the students assist to improve Clinical Scores for NP-C. The Clinical Score helps clinicians and researchers quantify disease progression, correlate potential biomarkers with disease status, and provide long-term outcome measures to evaluate therapeutic efficacy. A paper on this unique course, authored by the students and course instructors was published in 2011 by the prestigious open access journal, PLOS One. To view this paper go to: <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0023666>

Kasturi Haldar, Ph.D.

Director, Center for Rare and Neglected Diseases

Julius Nieuwland, Chair of Biological Sciences



Mark Your Calendar

May 12, 2012

The fourth annual event in honor of Ashton Friedl takes on a new time and place this year. The It Comes In Pink "PinkNic" will be held on May 12th from 11am – 4pm at the Richmond International Raceway in Richmond, Virginia and will include a BBQ, live music, and fun for the entire family! For more information and to purchase tickets visit www.itcomesinpink.org.

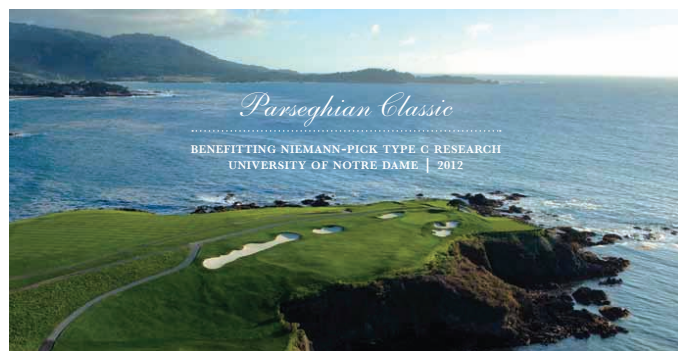


May 22 - June 22, 2012

Greg Crawford, Dean of Science at the University of Notre Dame is planning his third annual bike ride for NP-C. This year his goals are even more ambitious! His plan is to begin in Boston, Massachusetts and end in Southern California... covering more than 3000 miles while visiting NP-C families and Notre Dame Clubs along the way. These rides have been inspirational and have done so much to increase awareness of NP-C across the US. To follow Greg's ride visit his blog at: <http://blogs.nd.edu/gregcrawford/blog/>

June 7-9, 2012

The annual Michael, Marcia & Christa Parseghian Scientific Conference for Niemann Pick Type C Research will be held on the campus at the University of Notre Dame from June 7th through June 9th. Researchers and NP-C family members will attend 2 full days of presentations, discussions and collaborations on the latest developments in NP-C research.



June 22-24, 2012

The Parseghian Classic, a 3 day golf tournament will take place at the magnificent Pebble Beach Golf Resort. Golfers will play a round of golf at The Links at Spanish Bay and another at the Pebble Beach Golf Links. The all-inclusive event opens with a reception and dinner at Indian Village and closes with a reception and dinner at the Beach Club. Full golf and non-golf packages are available. Visit www.niemannpick.nd.edu for more information or call Cristi Ganyard at (574) 631-3070 or cganyard@nd.edu

June 25, 2012

The sixth annual Irish Legends Golf Tournament will be held at the Lost Dunes Golf Club in Bridgman, Michigan. Legends Ara Parseghian, Lou Holtz and the current fighting Irish football coach Brian Kelly will be participating in what no doubt will be another fabulous event. For information contact Angela Monger at (800) 628-9922, Ext 503 or acmonger@sap-corp.com



August 4, 2012

The fifth annual BReaKThru Fund Golf Outing will be held at the Lafayette Elks Country Club in Lafayette, Indiana. Hosted by the Smith family this event is held in honor of their 3 NP-C children, Braden, Reilly and Keaton. The proceeds from this event support NP-C research at Purdue University. For information contact Trent Smith at: info@breakthrufund.org

Heartfelt Thanks

A Touchdown for TY!

This annual fundraising event held in honor of Ty Quandt, took place on January 22nd at the College of Southern Utah. Once again this was an enjoyable evening showcasing the talent of local performers which included the Carroler School of Irish Dance, Charlie Franks, the UNLV String Quartet, Bethany Breed, Andrew Cogley and the Ross Family. A wonderful auction with over 50 great gift baskets paired with some tasty edibles rounded out the evening.

We wish to thank the tireless efforts of Verna Burrows, Ty's grandmother, and Verna's many friends from St George, Utah and the Las Vegas community who donate their time each year to raise funds that support critical NP-C research.

Uplifting Athletes at Northwestern University

Uplifting Athletes is a non-profit organization benefitting the rare disease community through outreach, research, education and advocacy. Chapters are run by college football student-athletes, providing them with an opportunity to gain practical job skills while learning how to leverage their assets and abilities to make a positive and lasting impact. A group of football players at Northwestern University developed a chapter of Uplifting Athletes in October 2010. After listening to Coach Parseghian speak at their homecoming last year, they chose Niemann-Pick Type C disease and the Parseghian Foundation as their focus. Chapter president Al Netter says that getting his Northwestern team to rally around Niemann-Pick Type C disease as a cause was easy. "I'm constantly getting guys asking how they can help out. They just want to get involved." The

Northwestern chapter of Uplifting Athletes held its first fundraising event, "Lift for Life" in July 2011 with the second event planned for this July along with several other fundraising activities. This chapter has been very active and we applaud their energy and commitment to fighting NP-C disease. For more information visit:

www.upliftingathletes.org/ua-chapter/northwestern



Athlete Tim Hanrahan at the Lift for Life Event.



Ashton Friedl with students at Saint Gertrude High School.

Students who care....The sophomore class of Saint Gertrude High School in Richmond, Virginia selected "It Comes In Pink" as their class outreach program. "It Comes In Pink" raises money for APMRF in honor of Ashton Friedl. A party featuring Ashton's favorite foods, pizza and cookies, was a great success while raising awareness and funds for NP-C. Thank you!!



Chicago....the American legendary rock band has been a longtime cherished friend of the Parseghian Foundation. For 17 years Chicago has generously donated a portion of concert ticket sales to APMRF. Their support of charitable causes is well known and we wish to thank them for their heartfelt contributions and their amazing music that continues to fill hearts and "colour our world"! For upcoming tour information visit www.chicagotheband.com.



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The Night Before My Birthday Book

*"The moon will soon rise,
and the sun has just set,
But it's still not my birthday yet..."*

The Night Before My Birthday Book, written by Joni Rubinstein, a longtime friend and supporter of the Parseghian Foundation, is a book that will help celebrate the special day of your cherished child and create a new tradition for families.

Joni's publishing company, Three Hearts Presents, is committed to supporting organizations that promote children's health, safety, and well-being through research and responsive services. For each copy of *The Night Before My Birthday Book* sold through their web site, or by mail, \$1.00 will be donated APMRF.

For more information on *The Night Before My Birthday Book* please visit www.nightbeforemybirthdaybook.com

